

Whereas many rare diseases are serious, life-threatening, and lack an effective treatment;

Whereas great strides have been made in research and treatment for rare diseases as a result of the Orphan Drug Act (Public Law 97-414);

Whereas the Food and Drug Administration has made great strides in involving the patient in the drug review process as part of its Patient-Focused Drug Development program, an initiative that originated in the Food and Drug Administration Safety and Innovation Act (Public Law 112-144);

Whereas although more than 450 drugs and biological products for the treatment of rare diseases have been approved by the Food and Drug Administration, millions of people in the United States have a rare disease for which there is no such approved treatment;

Whereas lack of access to effective treatments and difficulty in obtaining reimbursement for life-altering, and even life-saving, treatments still exist and remain significant challenges for people with rare diseases and their families;

Whereas rare diseases and conditions include epidermolysis bullosa, progeria, sickle cell anemia, spinal muscular atrophy, Duchenne muscular dystrophy, Tay-Sachs disease, cystic fibrosis, pulmonary fibrosis, many childhood cancers, and fibrodysplasia ossificans progressiva;

Whereas people with rare diseases experience challenges that include difficulty in obtaining accurate diagnoses, limited treatment options, and difficulty finding physicians or treatment centers with expertise in their diseases;

Whereas the rare disease community made great strides during the 113th Congress, including the passage of the National Pediatric Research Network Act (Public Law 113-55), which calls special attention to rare diseases and directs the National Institutes of Health to facilitate greater collaboration among researchers;

Whereas both the Food and Drug Administration and the National Institutes of Health have established special offices to advocate for rare disease research and treatments;

Whereas the National Organization for Rare Disorders, an organization established in 1983 to provide services to and advocate on behalf of patients with rare diseases, remains a critical public voice for people with rare diseases;

Whereas 2015 marks the 32nd anniversary of the enactment of the Orphan Drug Act and the establishment of the National Organization for Rare Disorders;

Whereas on February 25, 2015, more than 200 rare disease advocates shared their stories on Capitol Hill on behalf of the rare disease community and asked lawmakers to enhance public policy to help rare disease patients;

Whereas the National Organization for Rare Disorders sponsors Rare Disease Day in the United States and partners with many other major rare disease organizations to increase public awareness of rare diseases;

Whereas Rare Disease Day is observed each year on the last day of February;

Whereas Rare Disease Day is a global event, first observed in the United States on February 28, 2009, and observed in 84 countries in 2014; and

Whereas Rare Disease Day is expected to be observed globally for years to come, providing hope and information for rare disease patients around the world: Now, therefore, be it

*Resolved*, That the Senate—

(1) designates February 28, 2015, as “Rare Disease Day”;

(2) recognizes the importance of improving awareness and encouraging accurate and

early diagnosis of rare diseases and disorders; and

(3) supports a national and global commitment to improving access to and developing new treatments, diagnostics, and cures for rare diseases and disorders.

#### AMENDMENTS SUBMITTED AND PROPOSED

SA 264. Mr. SASSE submitted an amendment intended to be proposed by him to the bill H.R. 240, making appropriations for the Department of Homeland Security for the fiscal year ending September 30, 2015, and for other purposes; which was ordered to lie on the table.

SA 265. Mr. LEE (for himself and Mr. VITTER) submitted an amendment intended to be proposed to amendment SA 255 proposed by Mr. McCONNELL (for Mr. COCHRAN (for himself, Ms. MIKULSKI, and Mrs. SHAHEEN)) to the bill H.R. 240, supra; which was ordered to lie on the table.

SA 266. Mr. LEE submitted an amendment intended to be proposed to amendment SA 255 proposed by Mr. McCONNELL (for Mr. COCHRAN (for himself, Ms. MIKULSKI, and Mrs. SHAHEEN)) to the bill H.R. 240, supra; which was ordered to lie on the table.

SA 267. Mr. JOHNSON submitted an amendment intended to be proposed by him to the bill H.R. 240, supra; which was ordered to lie on the table.

SA 268. Mr. McCONNELL proposed an amendment to the bill H.R. 33, to amend the Internal Revenue Code of 1986 to ensure that emergency services volunteers are not taken into account as employees under the shared responsibility requirements contained in the Patient Protection and Affordable Care Act.

#### TEXT OF AMENDMENTS

**SA 264.** Mr. SASSE submitted an amendment intended to be proposed by him to the bill H.R. 240, making appropriations for the Department of Homeland Security for the fiscal year ending September 30, 2015, and for other purposes; which was ordered to lie on the table; as follows:

At the appropriate place, insert the following:

#### **SEC. \_\_\_\_ . PROHIBITION ON ISSUING SOCIAL SECURITY NUMBERS PURSUANT TO DEFERRED ACTION POLICIES.**

Section 205(c)(2)(B)(i)(I) of the Social Security Act (42 U.S.C. 405(c)(2)(B)(i)(I)) is amended by inserting “, except that the Commissioner of Social Security shall not issue a social security account number to any alien who is authorized to engage in employment in the United States pursuant only to deferred action policies set forth in the memorandum from the Secretary of Homeland Security entitled ‘Exercising Prosecutorial Discretion with Respect to Individuals Who Came to the United States as Children’ dated June 15, 2012, or the memorandum from the Secretary of Homeland Security entitled ‘Exercising Prosecutorial Discretion with Respect to Individuals who Came to the United States as Children and with Respect to Certain Individuals Who Are the Parents of U.S. Citizens or Permanent Residents’ dated November 20, 2014 (or any substantially similar policy changes issued or taken on or after the date of the enactment of the Department of Homeland Security Appropriations Act, 2015, whether set forth in memorandum, Executive order, regulation, directive, or by other action)” after “engage in such employment”.

**SA 265.** Mr. LEE (for himself and Mr. VITTER) submitted an amendment in-

tended to be proposed to amendment SA 255 proposed by Mr. McCONNELL (for Mr. COCHRAN (for himself, Ms. MIKULSKI, and Mrs. SHAHEEN)) to the bill H.R. 240, making appropriations for the Department of Homeland Security for the fiscal year ending September 30, 2015, and for other purposes; which was ordered to lie on the table; as follows:

At the appropriate place, insert the following:

**SEC. \_\_\_\_ .** (a) No funds, resources, or fees made available to the Secretary of Homeland Security, or to any other official of a Federal agency, by this Act or any other Act for any fiscal year, including any deposits into the Immigration Examinations Fee Account established under section 286(m) of the Immigration and Nationality Act (8 U.S.C. 1356(m)), may be used to implement, administer, enforce, or carry out (including through the issuance of any regulations) any of the policy changes set forth in the following memoranda (or any substantially similar policy changes issued or taken on or after January 9, 2015, whether set forth in memorandum, Executive order, regulation, directive, or by other action):

(1) The memorandum from the Secretary of Homeland Security entitled “Southern Border and Approaches Campaign” dated November 20, 2014.

(2) The memorandum from the Secretary of Homeland Security entitled “Policies for the Apprehension, Detention and Removal of Undocumented Immigrants” dated November 20, 2014.

(3) The memorandum from the Secretary of Homeland Security entitled “Secure Communities” dated November 20, 2014.

(4) The memorandum from the Secretary of Homeland Security entitled “Exercising Prosecutorial Discretion with Respect to Individuals Who Came to the United States as Children and with Respect to Certain Individuals Who Are the Parents of U.S. Citizens or Permanent Residents” dated November 20, 2014.

(5) The memorandum from the Secretary of Homeland Security entitled “Expansion of the Provisional Waiver Program” dated November 20, 2014.

(6) The memorandum from the Secretary of Homeland Security entitled “Policies Supporting U.S. High-Skilled Businesses and Workers” dated November 20, 2014.

(7) The memorandum from the Secretary of Homeland Security entitled “Families of U.S. Armed Forces Members and Enlistees” dated November 20, 2014.

(8) The memorandum from the Secretary of Homeland Security entitled “Directive to Provide Consistency Regarding Advance Parole” dated November 20, 2014.

(9) The memorandum from the Secretary of Homeland Security entitled “Policies to Promote and Increase Access to U.S. Citizenship” dated November 20, 2014.

(10) The memorandum from the President entitled “Modernizing and Streamlining the U.S. Immigrant Visa System for the 21st Century” dated November 21, 2014.

(11) The memorandum from the President entitled “Creating Welcoming Communities and Fully Integrating Immigrants and Refugees” dated November 21, 2014.

(b) The memoranda referred to in subsection (a) (or any substantially similar policy changes issued or taken on or after January 9, 2015, whether set forth in memorandum, Executive order, regulation, directive, or by other action) have no statutory or constitutional basis and therefore have no legal effect.

(c) No funds or fees made available to the Secretary of Homeland Security, or to any